

YOUR World Research

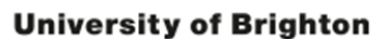
Insecurity and Uncertainty: Marginalised youth living rights in fragile and conflict affected situations in Ethiopia and Nepal

SUMMARY OF FINDINGS

DISABILITY



May 2019



Youth Uncertainty Rights (YOUR) World Research has carried out detailed qualitative and participatory research with some of the most marginalised young people across eight fragile environments in Ethiopia and Nepal. YOUR World Research shows that, when we include youth by listening to their views, a picture emerges of creativity and innovative ideas in the face of significant challenges. The research took place in 2016-2019, and has generated new knowledge about how marginalised young people perceive, navigate, negotiate and respond to uncertainty. By building on youth strategies, the research illuminates our understanding of young people's realities and rights, and how to support them to confront their feelings and experiences of marginalisation and find pathways out of poverty.

In Ethiopia and Nepal the national teams worked with a total of 1,000 young people including 500 in-depth and focused case studies – 500 young people and 250 case studies in each country. Four sites in each country provide evidence from youth in rural earthquake or drought affected fragile environments, conflict situations and of young lives on the streets of capital cities and smaller towns. Young people also provide illustrations of their journeys and reasons for migration in search of alternative futures.

In Ethiopia the research sites were: Addis Ketema in slums and with street connected youth; Hetosa in the drought affected zone; Woreta a transit town for migrants; and rural kebele's of Fogera Woreda, from where young people migrate to nearby towns. In Nepal the research sites were: Kathmandu to work in slums and with street connected youth; Sindhupalchowk in the earthquake affected area; and in Kapilvastu in the plains (Terai) urban and rural localities, with migration characteristic of each location.

DISABILITY KEY FINDINGS

Disability was found to be a major concern for youth in both Ethiopia and Nepal. The importance of understanding the varied dimensions and implications of youth being disabled themselves or living with family members with disability emerged in the research in both countries. The disability themed workshops held in Ethiopia as part of the verification and dissemination process involved groups of street connected and disabled young people, as well as researchers and policy makers. As a result of a National Youth Seminar, held in partnership with the Ministry of Women, Children and Youth, recommendations on disability were made a part of a process of developing inclusive national youth policy.

Disability is an umbrella term encompassing subgroups of people with disabilities, and varied categories of impairments, including physical, visual, hearing, mental health, and intellectual, which intersect with other socially defined diversities, such as gender, ethnicity/ caste, class, wealth and income status and sexuality. These variations may increase marginalisation and difficulties experienced, for example, women with disability, people with multiple disabilities, people with severe disabilities, disabled people who are poor, children and youth and and so on.

The term disabled youth/ young people is used here following consultation with disabled colleagues and young people rather than the term 'youth living with disability' which is also found in the literature.

The research shows how young people are disabled through the lack of provision as well as negative social attitudes and discrimination. While disability is often individualised in the way it is described, the broader impact on family and society needs to be considered as disability also affects households, families and broader social and economic networks of people who are non-disabled.

"In our area there is a blind woman. Her family hesitated to take her out of home for a walk let alone sending her to school. Now she is 17 years old, but she doesn't have the chance to go out and experience the outside world. The marginalisation begins from her family members themselves." (Yared, young man aged 24 years, Hetosa, Ethiopia)

ETHIOPIA

In Ethiopia, key issues from the research for disabled youth include education, migration, isolation and lack of support as well as stigma and discrimination. Many of these issues are concerns experienced by non-disabled youth, but the barriers and other difficulties are generally exacerbated for disabled young people, with implications for policy in mainstreaming disability across all areas.

Disabled young people from rural areas of Fogera and Hetosa in particular highlighted their difficulties in accessing formal education. These difficulties arose because of problems of physical access in schools, marginalisation in the classrooms, a lack of awareness of teachers about disability, and bullying from peers.

"I can't hear the teacher when he teaches due to my hearing problem. As it's a rural community most of those whom I talked to about my problem didn't appreciate it. Instead of proposing solutions they laughed at me. It was difficult to continue my education as there was no special support for those who have hearing disability like me." (Yetages, young man, aged 25 years, Hetosa)

The difficulties that disabled children and young people experience in school are reflected in their effective exclusion from local policy and decision making, and from other services. For example, Yeneneh, a young man from Fogera, spoke of his problems at school due to physical disability, but also about his frustration that he was not included in local government meetings. He further added that needed services were inaccessible. In their rural communities some of the young men and women living with disability feel that they are discriminated against and spoke of how others stigmatise them and call them names. They report this behaviour as the local norm. *"Some people in the neighbourhood insult me. They referred to me as senkalla [crippled]. I get angry with them. I feel bad about it. However, I often listen to such insults and keep quiet. My father also told me that I should expect that such things can happen to me."* (Betehon, young woman, aged 23 years, Fogera)

Some young people sought traditional healing and herbal medicine to cure ill health and disability and all talk of their lack of access to other medical services. Some youth from rural areas also talked about wanting to migrate like their peers but that they feel trapped because of their disability. Migration to small towns and big cities has become a livelihood strategy for disabled youth and their family members, but they find they then experience high levels of discrimination and stigma due to poor public understanding of disabilities. Migration of young people with disabilities has various consequences. These include dropping out of school and not accessing services, but also moving into street situations in order to survive in the urban areas to which they move.

If disabled young people have moved into a town or city they often lack contacts and feel isolated. They reported that services were hard to access, and they often felt alienated from what services they could find locally. In addition, some mentioned barriers such as not having identification cards or school certificates for their new lives in the city. On the other hand, some are linked with friends and show how having a supportive peer group and good contacts is beneficial. *"What brings the five of us together is that we share common problems. One of them is an Oromo and the rest of us are Amharas. Three out of the five of us have disabilities – leg injuries. At times when the two of us are not in good terms then another one of us serve as a mediator and try to help others reconcile. I share my happiness with another person with disabilities who is a Paralympics who is very good at sports and has a better working space given by the local government."* (Tarekegne, young man, aged 28 years from Addis Ketema)

In Ethiopia, a group of disabled young people held a workshop as part of the National Seminar in March 2019. In discussions they identified the most severe problems of youth with disabilities as:

- lack of support for disabled youth from different sectors
- lack of support from law enforcement bodies for disabled youth
- lack of response for questions of people with disabilities at different levels
- absence of assistive devices for their special needs
- the lack of participation of disabled people in policy making.

They also reported three less severe problems:

- service providing organisations are not comfortable for persons with disabilities
- lack of support for disabled people in employment
- lack of psychological support for disabled persons

The group also identified two other problems, first the lack of awareness raising programmes and events about disability issues; and second that organisations are not interested in employing disabled people.

NEPAL

In Nepal, key issues for disabled youth emerging from the research include healthcare, employment and income, as well as stigma and discrimination. The problem of multiple marginalisations was highlighted in Kathmandu. *"There is no secure place for the people who belong to Third gender with disability. Among Third gender also person with disability is more dominated and discriminated".* (Aadi, young person aged 23 years, Kathmandu). The research showed broad societal and family impact and implications of disability in addition to the consequences of conflict and accident.

Disabilities arising from the conflict caused uncertainties and migration, with young people and their families moving to seek income and treatment. *"My father was injured in Maoist conflict (12 years ago). It was very difficult time for me...He was fully injured....There was no huge money, treatment also not working. All the family shifted different places here to there, sometime Khotang, Udayapur, Kathmandu. I was with my parent here and there, no fixed place to live and do anything."* (Nima, young woman 19 years, Kathmandu).

Injuries sustained during the earthquake also caused longstanding disabilities. *"The house was destroyed due to earthquake. My mother was injured and taken to hospital. I cried a lot. Still chest bones and legs are broken. My father has also stone problem."* (Tina, young woman aged 17 years, Sindhupalchowk)

Young people reported family disabilities caused by accidents, which brought financial and other problems. *"My father is in Malaysia for another three years. My mother was married at 20 years old and now she cannot work after an accident."* (Binayak, young man aged 16 years, Kathmandu). Young people reported that after a parent became disabled taking over supporting the family and household. *"I am earning for my family and supporting them fully. My father can't do any work as he became disabled after accident. My mother did hard work when I was child and feed us but now she is also sick and could not work."* (Oman, young man aged 22, Kapilvastu).

The impact of disability across the household, intersecting with other social stigma, and poverty was described: *"My father cannot see, and my mother cannot walk properly. When I was 10 years old, I felt sad as I came to know that my father cannot see properly, though he got that problem before his marriage. His eye was very weak and then after the devastating earthquake, perhaps due to the shock of earthquake and thinking of societal taboo attached of having only daughters and lack of nutritional food during his childhood, he became completely blind."* (Pratika, young woman aged 15 years, Sindhupalchowk)

The broader family impact was also highlighted in urban Kapilvastu. Sabita was studying grade 11 but wants to work now her father, disabled through an accident, cannot work and needs money for treatment. Sabita faces gender discrimination. *"Now my father is sick. We don't have money, so I cannot study. My mother and father always tell me to study, but I don't want to study. They shouted at me whenever I say that I want to work in the factory. We need money for the treatment of my father. When my father becomes ill and we don't have money at home then I think that if I were a son, then we would not have these problems."* (Sabita, young woman aged 19 years, urban Kapilvastu)

Disabled young people faced interconnecting problems, for example getting access to healthcare and treatment, being frustrated that they could not earn, and feeling that they are becoming isolated. *"I fell in sickness time to time in my childhood. My parents did domestic treatment (dhami/jhakri) only. I did not get good hospital treatment as my parents are poor."* (Nita, young woman aged 15, urban Kapilvastu).

"When I was 3 years old, a motorbike hit me, I was severely injured. Thereafter I suffered with the diseases called Harniya....I think the health is important for life. If you have good health, then you can earn money." (Sijan, young man 25 years, Kathmandu).

Disabled young people also migrate for work with families or by themselves. The experience of one young man, who went to India for work and treatment but returned within three months because of leg problems since childhood, illustrates efforts and frustrations. *"While I walk I got pain in leg from my childhood. I went for treatment at local health post as I did not have money to go far and get good treatment. That gave relief for short period. Five years ago (at the age of 16) I was suffering with the pain very much. I went to India with the support of parents. I got good treatment as my health is improving now. Though, there is some pain still ... I felt very bad as I did not get good treatment due to lack of money in time."* He also mentioned the isolation: *"No one there for me to support if I fall on any bad situation. I have to live myself alone if I get any painful situation."* (Jasmin, young man aged 21, rural Kapilvastu)

Problems of access to, and the cost of, healthcare, alongside traditional beliefs and the lack of satisfactory answers from the medical system mean that families may seek help from various practitioners. For example, Teju who wants to work but needs support, and has limited mobility, reported seeking help from several health systems:

"I have a very strange disease, called 'Chhopne' [a patient becomes unconscious temporarily and traditionally believed as done by some bad spirits]. It started when I was five years old. When it happens, I feel as if the person who is talking to you or scenario fades away slowly and then faints. Or sometimes, I keep on talking to myself, but I am not aware. It stays for a few days. My parents have consulted Dhami-Jhankris [traditional shamans]. I was also taken to big hospitals and had done CT scan of my head. Nothing was found. I have also taken many medicines, but did not work. There is no specific time, place or reason so I do not know when it happens. It may happen right now talking to you, or sometimes, while walking on the street. It is very unpredictable. So I do not feel comfortable going to school. It also has happened many times in the school, too." (Teju, young woman aged 22 years, Kathmandu).

Mental health, particularly depression, was experienced as a disabling condition. Meena described it as the worst time in her life. *"I fell sick [depression] at different times, which is problematic time for me. Last year, I fell sick which was biggest problem in my life. I went for treatment and slowly improved. I am taking medicine now also."* (Meena, young woman aged 17 years, urban Kapilvastu).

Family dynamics, violence and abuse are important. *"There was no food and clothes at my home. I did all the household work from my childhood. I went for labour work in the age to 10. I was beaten from my step mother and my hearing capacity was lost [in left ear from being hit]. I have no such dream except living safely with family."* (Lajana, young woman aged 20 years, rural Kapilvastu).

KEY MESSAGES FOR POLICY AND PRACTICE

Key findings from our participants in Ethiopia and Nepal include problems in education, access to healthcare and services, lack of employment, migration, isolation, lack of support, stigma and discrimination.

It is important to emphasise that many of the problems of access to healthcare, employment and income, as well as discrimination, are also experienced by marginalised non-disabled youth, but the situation for disabled young people is generally exacerbated through a range of disability related social barriers, stigmas and socio-economic concerns.

These messages for policy and practice have been drawn from the research and supplemented by specialist workshops in Ethiopia with disabled young people, researchers, policymakers and expert practitioners.

The broader impact of disability on families and communities as well as individuals has implications across all areas of policy and practice. **A key message** is the need to **mainstream disability issues and responses** across all levels of government, organisations and services. Government and non-government organisations and departments need take into account the effect of their policies, services and practices on disabled people of all ages, particularly for the world in which disabled children and young people are growing up, and make provision for similar oversight in the private sector.

Mainstreaming disability issues requires specific actions to address a number of key problems experienced by disabled young people.

Education: the experiences of disabled youth in education have included marginalisation, alienation, isolation, lack of support, poor treatment by teachers and bullying by peers as well as accessibility barriers getting to school and difficulties do to the layout of, schools once a disabled student reaches the building. Many drop out or fail examinations. Major changes are needed in the training and attitude of teachers and other personnel, including dealing with bullying, and in the social environment of schools. Access to schools needs to be addressed along with the design and changes to buildings where necessary.

Employment: young people report difficulties in gaining employment because of their own or family disabilities. Government and non-government organisations can take the lead in changing employment practices to ensure disabled applicants are welcomed and appropriately supported. Other employers need encouragement and oversight to address disability issues such as incentives to guarantee disabled youth inclusion and an equal chance in the job sector (such as rewarding businesses that hire a significant number of people with disabilities).

Healthcare: young people report problems in accessing healthcare because of cost, distance or location, in addition to the need for relevant information. Accessibility of healthcare needs to include mechanisms to deal with treatable diseases that are increasingly seen as the cause of a variety of disabilities. Disabled young people are also at higher risk of contracting diseases where they are restricted from accessing information and gaining appropriate knowledge for prevention and early treatment. This includes contracting HIV and other sexually transmitted diseases, because they are often not included in sexual and reproductive health classes or outreach efforts.

Infrastructure: in many places buildings, roads and transport is not accessible or effective for disabled people and this has a particular impact on disabled children and youth needing to attend education, find employment, travel to health facilities and other services. Changes in existing infrastructure and new developments need to specifically take account of the requirements of disabled people.

Participation: disabled young people report being excluded from participation in local decision making and policy making. The development of participation practice for young people including involvement in community and government policy and decision making needs to specifically include provision for participation of disabled young people.

Support: disabled young people report a lack of support, including psychological support, in various aspects of life, particularly in areas such as education, employment, health services, as well as in participation in public life. Services and provision are needed to address and improve support for disabled youth, which should include particular attention for those who have migrated.

Law enforcement: disabled young people are engaged in a variety of situations and work. For many this includes street connected. They report a lack of support from law enforcement bodies. Attitudes and practices need to be addressed and change to provide attention to, and positive support for, the needs of disabled youth in communities.

Stigma and discrimination: The experiences of marginalisation, stigma and discrimination of disabled young people, is often extended to their family and household. Shifting and changing attitudes towards disability need to be taken up through awareness raising and behaviour change programmes in government and non-government services and in communities, in the private sector and more broadly, as part of initiatives for the general public.

Data collection: data is needed on disability issues in order to respond to the needs of, and properly provide for, all ages of disabled people. Disaggregated data collection is needed and a programme for this development, led by government throughout departments and services.

UK Team

Dr Vicky Johnson, Principal Investigator, Goldsmiths
Dr Andy West, Senior Research Fellow, Goldsmiths
Signe Gosmann, Research Officer/ Fellow, Goldsmiths
Prof. Andrew Church, Adviser, University of Brighton
Dr Mark Erickson, Adviser, University of Brighton

Ethiopian Team

Dr Melese Getu, National Research Lead, Addis Ababa University, Ethiopia
Amid Ahmed, Debre Markos University
Milki Getachew, PhD Student, Goldsmiths

Nepal Team

Dr Sumon Kamal Tuladhar, National Research Lead, Previously Unicef and CERID, Nepal
Sabitra Neupane, HomeNet Nepal
Shubhendra Man Shrestha, PhD Student, Goldsmiths

Partners for Ethiopia

CHADET, Director, Anannia Admassu
ChildHope UK, Director, Jill Healey

Partners in Nepal

ActionAid Nepal, Director Sujeeta Mathema
Research Centre for Educational Innovation and Development (CERID), Tribhuvan University, Nepal

Advisers on disability:

Dr Mark Carew, Leonard Cheshire
Prof. Nora Groce, University College London